

# ICO consultation on the draft right of access guidance 2019

## Response by Access to Care Records Campaign Group



<https://www.accesstocarerecords.org.uk/>

ACRCG is an association of individuals dedicated to providing better access to care records for adult care leavers, working with adult care leavers and organisations to lobby government for changes in law and regulation.

We welcome this draft guidance and consider that it sets out clearly the rights of individuals to know what personal data is held by an organisation about them and the responsibilities on organisations to respond to a request to see that data. It establishes both clear principles, explanations of the legal requirements and the need for systems to both secure personal data and ensure its retrieval. We read it has having an 'enabling' approach to sharing information held on records, which is encouraging. We agree with MIRRA submission that the focus of the guidance is on process and procedure which is important but does not address the impact on an adult care leaver if the response to their SAR is thoughtless and unsupportive at best or the exercise of discretion to provide third party information is defensive and unnecessarily redactive.

We understand that the guidance is in general terms and that the ICO is not at this time issuing sector specific guidance. We share the view of MIRRA that it would be helpful to have supplementary guidance regarding releasing personal data held on social care record, placing the adult care leaver at the centre of decision making and the balancing of privacy rights of others.

One of the significant barriers that adult care leavers face when making a SAR to find out about themselves and their personal and family history which the organisation holds in the individual's care records is the reality that the response from the Data Controller is to treat the request as a standard SAR and to approach the task very narrowly. Our Freedom of Information survey to local authorities in England in 2017 demonstrated that of those that responded three fifths had no records of the number of Subject Access Requests [SARs] made in a 12 month period by adult care leavers. Most local authorities did not keep data about the number of SARs from care leavers in an annual period and appeared to have no dedicated process and systems in place to respond to such a request. The needs of adult care leavers are unique and, in our view, the Data Protection Act 2018 is not designed to address their right to know what personal information and relevant family information is held about them on care records. The issues that these people face include:

- defensive redaction of information particularly third-party information, often information which is already known to them

- defensive exercises of what should be an enabling discretion to provide third party information – both in the decision making about whether to get consent from the third party and about sharing third party information without consent
- failure to understand what information on care records is not ‘protected’ information
- an overuse of the ‘serious harm’ test to withhold information, sometimes not properly informed by professional health advice about the individual’s current health and circumstances. And as MIRRA points out, based on their research with adult care leavers, the more serious harm is the impact of withholding information on the emotional well – being of the person making the request.
- lack of sensitivity about explaining language, terms or professional jargon used in documents in their case file: this is particularly so for older adult carer leavers who are distressed by terms and descriptions about them and their family that were used in the past
- lack of support to the individual during the SAR process and after their care records have been shared.

The guidance is targetted to DPOs. [p3] We ask that the ICO makes this guidance known widely beyond the usual data governance remit. Preparation of responses to SARs from adult care leavers made to a local authority or sometimes in the voluntary sector is often done by a social worker or an administrative officer who has limited knowledge of an individual’s personal data rights. It would be useful to inform Directors of Children’s Services as well as data governance officers of this guidance. It is for this reason that we also believe that sector specific guidance issued under the authority of the ICO would significantly improve both decision making and practice.

Below we comment on what is welcome and where we consider there are limitations or omissions in the current draft. We hope this is an acceptable way forward rather than using the standard consultation form. We welcome this guidance and its enabling tone: we believe that supplementary guidance would address the unique rights and needs of adult care leavers and reduce the ‘unfairness’ of the present practice and decision making.

Page number	Comment
3 – supplementary information	We welcome the clear statement that a SAR is a ‘fundamental right’, together with the clear statement regarding supplementary information. For older care leavers, the records may not be clear about with whom their Personal Data has been shared and it would be useful if it was stated that the organisation should make reasonable efforts to clarify this when responding and also identify, where possible, the source of information.
4 - information	For care leavers this is often frustrating, especially if the organisation

relating to the individual and another person	takes a restrictive or unimaginative approach regarding getting consent: in our experience too often it decides not to seek third party consent. This is compounded if the the Data Controller then exercises their discretion to share without consent in a narrow or negative way, adverse to the rights of the adult care leaver. It would be helpful in the later section at p39 if there were examples of the 'balancing test' for sharing all the information in such circumstances as redaction may render the quality or 'sense' of the relevant information meaningless or, at its worse, misleading.
7 – preparation for SARs	The bullets/actions are welcome, particularly the emphasis on an Assets Register, Training and Retention policies. Regarding retention it would be useful to include a reminder that in some circumstances [eg care records] there is a statutory time limit for retention of records which 'reshapes' the principle to hold data only as long as is necessary. An Assets Register is very important especially for older care leavers where their care records may have been transferred from another agency or carelessly archived, so this is an important message to Councillors, Ofsted and Directors of Children's Services. See above our point about wider dissemination of the guidance. Where records were made in the 1960s and 70s or earlier many LAs have poor retention and retrieval systems as the IICSA has demonstrated. This has a profoundly adverse impact on the well-being of an adult care leaver making a SAR.
9 – the individual does not have to say why and what they intend to do with the PD	This is very welcome. In ACRCG's experience and also that of CLA and other support groups, if the LA is fearful that the reason for the request is to seek redress or an apology or litigation, the preparation of their response is overseen and possibly managed by their public indemnity insurers. This reinforces practice which is restrictive, defensive and unhelpful leading to unnecessary redactions, delays and distress for the individual exercising their fundamental right.
12 – SAR made through 3 <sup>rd</sup> party portal	The voluntary sector and individuals have an important role in assisting adult care leavers to make a SAR. It is important that guidance states that the organisation should set out in its SAR policies what evidence from the third party [supporter] will satisfy the ID requirements. If this is unduly complicated, the individual making the SAR feels under pressure to not use a third party to support them through the process.
13 – child's rights	This is helpful as children in care may also want to see the PD held about them on health or education files, as well as care files.
16 – 18 – time lines to respond	The guidance is clear about timelines: we welcome the statement that a request is not complex solely because the individual has requested a large amount of information. This is, too often, used as a reason to delay responding. It would be helpful to expand this section to give an

	example to show that if there is a lot of PD material held, agreement can be made to release material in sections. Good practice is to work with the individual to find a way to do this effectively without putting them under pressure to say what they want first or to try and restrict what is shared, especially if they do not know what personal data material is held.
19 – person with disabilities	For care leavers, undertaking a SAR requires courage and resilience and, whilst they may not have an identifiable disability, the emotional and mental stress may be considerable. This section could be expanded to include examples of providing suitable emotional support if that is what the individual wants. The reality for many adult care leavers is that they are asking for records from an organisation with whom they may have had a troubling and dismissive experience of care. The organisation should be able to show that they have taken this into account, being sensitive to the individual's needs, both practical and emotional.
19 & 20 - ID	Verification requirements, which we accept are necessary, may pose barriers for adult care leavers. It is important to stress flexibility, taking into account the circumstances of the individual. Some will not have a passport, may not have documents about their birth date or utility or other types of usual ID documents. Care leavers in prison may have difficulties in establishing ID and it is important that local authorities and similar organisations have clear policies and practices for staff working with SARs about flexibility in establishing ID. It is also important to understand the internal procedures within the prison estate regarding ID documents.
P23 – retrieving PD	Establishing a high expectation to retrieve the person's PD is very helpful.
25 – no technology exemption	This is clear and helpful. It would be useful to add that some PD is subject to rules about its retention which should be covered in the organisation's retention and backup policies. In the case of this PD, it is important that methods for backing up records, some of which may now be in a fragile state, are sustainable and accessible in the future and that currently generated e-documents have been assessed to have long term viability both for enduring and for means of accessing eg should not become 'inaccessible' through lack of data software or systems. Migrating data across systems must address the integrity and security of the systems used as part of the 'fit for purpose' data migration methodology.
25 – deleted information	It would be useful to state that care records [and similar] cannot be deleted and that retention and storage policies must be clear. The retention period varies across the 4 nations and local authorities should

	be encouraged retain such records beyond the prescribed date. This is an area where we think ICO could be influential when Ofsted create standards or expectations regarding archiving care records.
28 - offence to amend/delete to avoid disclosure	This is useful reminder.
30 – methods for sharing information	We welcome statement that the ‘..individual should not have to take action to receive the information (e.g. by collecting it from your premises) unless they agree to do so.’ The practice of how the files are ‘shared’ varies widely across local authorities and is sometimes handled very insensitively. We endorse the clear statement that that the individual should not have to have the necessary software to ‘read’ the data. Some care leavers will not have access to either the software or the hardware to read e-documents and it is important that the onus to find an acceptable way to ‘access’ the information is on the organisation not the care leaver.
33 – explaining information provided	The principles are very helpful. For older care leavers language and terms used in care records may now read offensively and show disrespect for the individual and their family members. It is important to explain not only professional jargon or acronyms but also outdated terms which would now not be acceptable in professional records. We would welcome this section being extended to include a statement about this.
35 – excessive and manifestly unfounded	We welcome the case by case approach. This ‘reason’ for exempting sharing PD is open to wide and insensitive use. A adult care leaver may make several SARs at differing stages of their life journey as their personal circumstances alter; some will not be able to keep hold physically of their care records and will need to have that material a second or third time or more. This should not be interpreted as either unfounded or excessive. Hence, the circumstances of the individual when exercising their fundamental right need to be properly considered. It should not be used to avoid responding to the SAR or seeking to impose a fee.
39 - 3 <sup>rd</sup> party PD: consent: exercise of discretion	We welcome this section because this is particularly relevant to adult care leavers and our aim is to encourage Data Controllers to be more enabling in the way they exercise their discretion to share third party data. Practice about how and who makes decisions balancing the privacy rights of a third party and the fundamental rights of the individual varies within and across local authorities. Data governance officers may be less restrictive than social care professionals. This directly impacts on the rights of adult care leavers collectively and as individuals. Too often, it depends on the empathy of the particular data



	<p>governance officer dealing with the request or the social worker to persuade their managers, who are more concerned about the risk of a DPA breach, to overcome what becomes a pervasive culture of defensive 'disclosure' practice.</p> <p>Public indemnity Insurers also tend to create a defensive culture within the local authority. This particularly impacts on how discretion to share without consent or decisions about seeking consent are made.</p> <p>Frequently no one properly ascertains what 3<sup>rd</sup> party PD is already known to the adult care leaver or partially known or is in the public arena. Thought is not given to how 3<sup>rd</sup> party data can be shared without identifying an individual.</p> <p>It is helpful to state that refusal from the 3<sup>rd</sup> party does not of itself remove the discretion to share and it would be helpful to set out in more detail or give an example of how to balance the care leaver's Article 8 HRA right to family life and the 3<sup>rd</sup> party's Article 8 right to privacy, making a decision which gives proper weight to the welfare and interests of the adult care leaver. It would be useful to include a statement that the ICO, responding to a 3<sup>rd</sup> party complaint about data breach, will consider, taking account of all the circumstances, whether the exercise of discretion was 'justifiable' or provide an example of the approach by the ICO.</p>
41 - confidentiality	<p>The warning that there is no presumption of confidentiality merely because a document is so marked is useful. See our comments directly above. We would welcome an elaboration on how decision making is approached so that the decision made is 'justifiable' and is unlikely to be viewed as a breach of confidentiality.</p> <p>The example on p43 does not spell out the parameters for decision making about giving information about the family member.</p>
42 & 43 – health , social work and education data.	<p>The reminder that PD of professionals acting in their employed or professional capacity should be shared is useful.</p>
44 – relevant factors	<p>This is helpful and it would be useful if this section was linked with other sections about decision making.</p>
54 - exemptions	<p>'Best interests' is a vague concept, and in a culture where practice is defensive, it is likely to be interpreted narrowly and not in the interests of wider sharing of information. The needs and rights of the individual making the SAR should be at the centre of decision making about best interests. Sharing information with a parent or carer may place the individual at greater risk.</p>
64 – serious harm test and	<p>This section is useful, and it will be important for agencies and professionals to be accountable for decision making when applying the</p>

exemption	exemption so that it is not left to individual judgement which is likely to cause inconsistent approaches and reinforce poorly informed decision making.
72 – social work data	This section is helpful but may need more examples to improve practice and to ‘debunk’ myths about what is meant by social work data and social work functions. The statement at the end of p72 is clear but because decision making about sharing 3 <sup>rd</sup> party information is erratic and too often restrictive it would be useful to expand on the process in the relevant section of the guidance – see above.
73 – expectation of confidence	Inevitably this concept applies both ways and we try to encourage practitioners to think into the future about getting consent from family members/3rd parties to share information with a child or young person currently in care at some future point. This apparent lack of consent is often seen/used as a barrier to sharing in the case of a SAR from an older adult care leaver when such practice was not in place. The apparent lack of explicit consent is not put in context and is used as a reason not to exercise the discretion to give the 3 <sup>rd</sup> party information.
74 – prejudice carrying out social work test	This test or concept - the request would be likely to prejudice carrying out social work because it would be likely to cause serious harm to the physical or mental health of any individual – is not properly understood by social workers and their managers. It would be helpful to link back to the section on how the risk of ‘serious harm’ test needs to be properly evidence based by the judgement of a qualified health professional. The lack of support services for the individual making the SAR should not become a substantive reason for deciding that there is a risk of ‘serious harm’ and decision making should be informed by clear guidelines and senior data governance decision making approval. It would be helpful if the detail regarding this was addressed in the guidance.